

Manchester Learning Disability Partnership

Think Quality: The establishment of a consumer group to contribute to quality within Manchester Learning Disability Partnership

Summary of key findings

August 2001

Introduction

This report describes the establishment of *Think Quality*, a group of people with learning difficulties¹ established to contribute to service quality within Manchester Learning Disability Partnership (MLDP). This group works in parallel with the service-wide *Quality Action Group*. The establishment of this group was the focus of a research project that aimed:

- a) To record the process and content of meetings
- b) To identify barriers and factors which facilitate the group's development over time
- c) To explore the impact of the group's discussions and ideas on service delivery.

The research used participant observation (a qualitative observational technique which involves the researcher in the activities of the group). In addition, a group discussion was held with the *Think Quality* members to obtain their feedback on the group; whilst the group organisers contributed to the development of the key themes and implications.

This report draws on observations from meetings held in 2000 and two more recent meetings. *Think Quality* has discussed a number of topics during this time period (including support services, choice, decision-making, group rules, transport, support workers and personal planning). This report does not focus on the content of these discussions². Instead, the report summarises issues relating to the group's development, and draws attention to implications for the development of similar groups and service providers. A *checklist for consultation* is included to help draw attention to key issues to consider when establishing a similar group.

¹ The term 'people with learning difficulties' is used as it is the term preferred by some people with learning difficulties (Goodley, 2000)

² A summary of these discussions is available from Jackie Kilbane. See page 10 for contact details

Key findings and implications

◆ The importance of consultation

Consultation is important to share power and control with people receiving services and to reduce any potential 'mismatch' between service provider and service recipient views about the processes, structures and impact of services. Government guidance emphasises the importance of involving those who use health and social care services at all levels, from decisions over individual support to planning and purchasing services. The recent White Paper *Valuing People* (Department of Health, 2001) reiterates this message for people with learning difficulties.

Implications: It is important to be clear about the reasons for consultation. Consultation should not be a tokenistic response to policy guidance. It is important to hear people's stories about their experiences in order to highlight the impact of service delivery, and to embed user views in service development.

◆ Consultation methods

Think Quality was formed due to recognition that consultation within MLDP was often in terms of one-off consultation exercises. Previous attempts to involve people with learning difficulties in the existing service forum on quality issues, QAG, were unsuccessful due to the inaccessibility of the format and content of meetings.

Implications: Forming a group is not the sole means of consultation, nor does the existence of such a group absolve service providers from consulting in other ways. A range of methods of involving consumers should be considered (for example, representatives on service groups, consumer conferences, and individual consultation). Consultation should be embedded in all levels of the service and should not be seen as the responsibility of one group. It should be part of routine practice to consult and act upon the findings of consultation.

◆ The role of the group

The envisaged role of *Think Quality* was

- ◇ To monitor the work of the existing staff dominated *Quality Action Group* (QAG)
- ◇ Provide a vehicle for input into QAG discussions and agenda formulation
- ◇ Comment on service matters including new or developing policies

The group has commented on topics being discussed by QAG and service issues such as transport. In addition, the group appears to play a wider role, providing a forum for information seeking and provision, social contact and a form of activity. Individuals within the group also appear to have grown in confidence.

Implications: It is important to be clear about the primary role of the group; for example, whether the primary role of the group is to inform discussions about quality in the service or to develop self-advocacy skills. Clarity about the primary role of the group will aid decision making, helping to conceptualise and resolve issues that arise as the group develops. Differing perceptions about the role of the group can lead to misunderstandings, both within the group and by service providers. The primary role does not exclude the group from developing other roles, and members may still develop self-advocacy skills.

◆ **Planning**

The first meeting took place five months after the initial agreement to establish the group. The planning stage involved:

- ◇ Discussion and decision-making about the group role, provisional group name, responsibilities and practicalities such as venue and facilitation
- ◇ Gaining management approval for financial support and release of staff time
- ◇ Recruitment of members

Quality Development Officers (QDOs), the learning disabled representative from QAG and the researcher were involved in the planning stages.

Implications: It may take time to establish a group. A working group can be established to discuss issues and to make decisions. Decisions made by any working group are not final - once the group is established it is likely that members will want to shape the group's development. Any working group should include at least one learning disabled member.

◆ **Recruitment of group members**

Group members were recruited through a variety of methods: visits to MLDP Consumer days³ and groups of people with learning difficulties; and correspondence with community learning disability teams and networks for suggestions for membership. An initial meeting was held with people who were interested in joining the group to discuss the role of the group and timing of meetings.

Implications: Consider whether the group needs to be representative of the population the service supports or if it can be self-selecting. Although, ideally people should be given an equal opportunity to attend the group, this may lead to a large group. People may wish to attend as representatives or as an interested individual. As the group develops it may need to consider whether membership is closed to current attendees or whether other people can join the group.

³ These are days organised for people living in MLDP supported housing

◆ Venue

The group has met at four different venues.

Implications: Choice of venue is important. Important factors to consider include whether a venue: is in an accessible non-service community setting and demonstrates to group members that they are valued. The availability of refreshments, size of the venue and whether there will be any distractions are also important. These factors have to be balanced against available resources.

◆ Size of the group

The size of the group dropped from 26 people at the initial meeting to a core membership of approximately 14 people (excluding organisers). The size of the group has important implications for both facilitation and participation. The number of people attending may fluctuate due to conflicting commitments or decisions to cease attending.

Implications: If membership is larger than approximately 14 people it may be necessary to divide into smaller groups. Members may not be supported to give apologies – liaising with support staff and families may prevent this happening. It would be useful to gain information on the reasons people decide to leave the group.

◆ Ways of working

Initial meetings of the group have focused on developing ways of working within the group (for example, roles within the group, decision-making, communication and support, group rules, choosing a group name, recording meetings). The current focus is upon developing ways of working with the wider service (i.e. QAG, senior management, requests to visit the group). There has been one joint meeting between *Think Quality*, QAG members and senior management. At this meeting *Think Quality* members expressed a desire that they be involved in discussions about quality and policy from the outset, rather than be asked to comment on policies that have already been developed. Information sharing between the two groups was also discussed.

Implications: There needs to be a record of group meetings. This can take the form of notes written during the meeting or audio-taping meetings (with permission from group members). Written records need to be in accessible language and ideally symbols included. Tapes of the meeting provide a record for people who do not read or who are visually impaired. It is necessary to consider from the outset how information from the group will feed back into decisions about service provision. There needs to be management commitment to act on the group's ideas and suggestions so that consultation is not tokenistic.

◆ **Format of meetings**

Think Quality meetings take 2 hours (with lunch available an hour beforehand). The typical format of a meeting is:

- Welcome and introductions
- Sharing of news
- Discussion
- Break for refreshments
- Discussion
- Summing up
- Next meeting

Implications: Meetings do not have to follow a typical meeting format (apologies, previous minutes, matters arising, agenda items etc). A more relaxed format may be more appropriate, with time for sharing of news and social interaction. To facilitate discussion, meetings may be longer with frequent breaks. It may take several meetings to explore a topic. It is important to summarise discussions from the previous meeting and to talk about the plans for the next meeting at the end of the current meeting.

◆ **Facilitation and organisation**

Think Quality has been organised and facilitated by four QDOs and the learning disabled member of QAG with some input from the researcher and other MLDP staff. Although employed by MLDP, the QDOs are not involved in the direct support of individuals within the group. Within the service it is part of the QDO role to cast a critical eye over services and to influence service development. They have experience facilitating groups and can draw on their knowledge in which services operate and prior experience of working with people with learning difficulties. Therefore potential conflicts of interest are reduced.

The facilitators draw on a range of skills including: seeking information, facts and opinions; involving people in discussions; summarising and expanding; clarifying and interpreting; proposing and explaining; and re-focusing, guiding and directing discussions. At present they also feed back *Think Quality* discussions to QAG, as attempts to involve group members in this process have been unsuccessful. The facilitators draw out relevant points for the service from the personal stories of group members, checking and confirming their interpretations with group members.

Organisation also includes administrative tasks such as dealing with travel expenses, writing up meeting notes and letters about future meetings. There is much invisible work 'behind the scenes'. This includes planning meetings, meeting social and personal care needs, and following up issues relating to individual attendance with service providers and families (e.g. transport,

understanding communication and support needs to enable an individual to continue to be part of the group)

Observations from recent meetings indicate that the boundaries between group organisers and members are more fluid than at earlier group meetings. Members are playing a more active part in meetings, taking on roles such as involving others, explaining and supporting each other.

Implications: It is important that people who do not directly provide care or support to group members facilitate the group, as this may cause conflicts of interest for facilitators and a lack of honesty by members. If facilitators do provide direct care or support it is vital that there is awareness of the tensions and dilemmas this may cause. In such a situation, organised and effective management and supervision of facilitators would be necessary.

Establishing and organising a group involves a range of administration and facilitation skills. There is much 'invisible' work. It can be time-consuming to establish and maintain a group. Consider who has the necessary skills, how much time it may take, implications for existing workloads, and what administrative support is necessary.

Group members are likely to develop important roles within the group as the group develops (for example, supporting other group members, ensuring group rules are followed, and helping with facilitation, administration and organisation). This may lead to shifts in power relationships within the group and it would be useful to consider how this will be managed.

◆ **Maintaining interest and stimulating discussion**

It could be difficult to explain complex, abstract concepts relating to quality (e.g. choice and control), service delivery models and jargon to group members. Use of role-play and group tasks were used to make issues more concrete and to link topics to group members' day to day experiences.

Initially it could be hard to stimulate discussion amongst all members. Using open questions directed towards the group rather than closed (yes/no) questions directed at individuals was a useful means of stimulating group discussion.

Implications: Different creative methods such as role plays, the use of drama, singing and group exercises can help to make issues more concrete and relevant, helping people relate their experiences to the issue under discussion. Use of open questions directed to the group as a whole can encourage discussion.

◆ **Communication**

Group members use a variety of communication methods. Most members use verbal communication, one member uses a communication machine, and another uses sound and gestures. It takes time for a group to develop means of communication which involve everyone. Lack of confidence may also be a barrier to communication. Several members are now contributing to discussions who were reluctant to join in at earlier meetings. One member of the group was initially supported by a worker to contribute in meetings, and now attends independently, whilst another seems to have been encouraged to join in discussions by testing the microphone used to tape meetings.

Implications: Communication is the responsibility of everybody within the group. People communicate in different ways and it is important to obtain the views of people who might not get the opportunity to contribute in traditional meeting formats. Liaising with speech and language therapists and support staff can help develop understanding of communication methods. Using information gathered in person centred planning can also be a method of eliciting the views of people who do not use speech to communicate. It may take time for quieter, less confident, members to contribute to group discussions.

◆ **Speakers and requests for involvement**

Several people have visited *Think Quality* to gain the group's views. For example, the group has commented on transport, the recruitment of support workers and the design of a calling card.

Implications: Be clear about speakers' reasons for visiting the group. Speakers should visit the group to discuss issues, not to promote their service. Speakers should be briefed on what is expected of them (for example, using accessible language). It may be more appropriate for speakers to consult directly with the people they support, rather than a generic group.

◆ **Time-scales**

As discussed earlier, the planning of a group can take time. Initial meetings have focused on group development in addition to discussions on specific topics. The current focus is on developing ways of working with QAG and MLDP.

Implications: Group development takes time, whilst exploring an issue is likely to take more than one meeting. It is unrealistic to expect the group to respond to requests for involvement within a short time frame. It may be necessary to allow 2-3 meetings to discuss each issue.

◆ **Payment**

Group members are likely to be giving their time for free. Payment above a certain amount may affect benefits.

Implications: As a minimum, travel expenses should be provided for participants. A nominal payment that would not affect benefits could also be considered.

Support workers and personal assistance

Support workers were asked to leave at the first meeting unless people wanted them to remain. This was to ensure that there was a safe environment where people could speak honestly and critically about the support they receive. This led to some tensions with support workers who may not have understood the reasons for being asked to leave or due to issues surrounding risk. However, support workers may play an important role with personal assistance and supporting communication.

Implications: People with learning difficulties may be less honest if support workers are present at meetings. However, support workers may also play an important role in supporting people to attend and contribute to meetings. Being clear about support workers' role and explaining the reasons for their exclusion may minimise tensions. It is important to be aware of, and to address, personal assistance requirements so that people can be included in meetings.

◆ Implications for Manchester Learning Disability Partnership

Establishing *Think Quality* reflects both a commitment by the service to consult with the people it supports, and a response to policy guidance. Although there have been difficulties establishing the group, the project reflects progress in methods of consultation from one-off events to a continuous approach. It is one of several methods of consultation that should inform service delivery. There has been much written about collaboration and user involvement but not much information on how to achieve this with people with learning difficulties. The focus has tended to be on the development of self-advocacy groups rather than groups whose primary role is to comment on quality issues.

The success of *Think Quality* and the strength of MLDP's commitment to consulting with people with learning difficulties will depend in part on whether the service acts upon what the group says. The group should not exist to rubber-stamp what has already been decided by the service but to contribute to policy development in a meaningful way.

It is vital that management understands the group's role and the time commitment involved for group development and discussions around topic areas. Occasional visits to the group can only provide a snap-shot of the group.

It will take more time for the group to develop further and to evaluate any impact made on service delivery. It is possible that the group will become more self-facilitating over time, needing less input from staff. However, this is likely to take some time.

Checklist for Consultation

The following are key issues to consider when establishing a consumer group of people with learning difficulties.

Role
<ul style="list-style-type: none"> • What is the primary role of the group? • What other roles might the group develop?
Venue
<ul style="list-style-type: none"> • Is the venue accessible? • Is the venue in a non-service, community setting? • Does the venue demonstrate to group members that they are valued? • Are refreshments available? • Are there any distractions (e.g. noise from other venue users)?
Organisation and Facilitation
<ul style="list-style-type: none"> • Who will organise and facilitate the group? Do they have the skills to establish and maintain a group? What are the implications for their workload? • If there is a working group, does it have at least one learning disabled member? • Is there any administrative support available? • If the group organiser(s) directly provide care or support to group members, have potential conflicts of interest and the impact on group members been discussed? Have effective management and supervision been arranged?
Payment
<ul style="list-style-type: none"> • Are travel expenses provided for participants? • Is there a possibility of payment for group members?
Size of the group
<ul style="list-style-type: none"> • If the group is larger than 14 members is it possible to divide into smaller groups? • Are mechanisms in place to get feedback on why group members leave?
Ways of working
<ul style="list-style-type: none"> • Do meetings enable a more relaxed format with time for news sharing and social interaction? Are there frequent breaks? Is enough time devoted to discussing each topic? Are realistic time frames given to respond to requests for involvement by the group? • Have a range of creative methods been considered to make issues under discussion concrete and relevant? (e.g. role play, drama, singing, group exercises) • Will a record of meetings be kept? • Are written records in accessible language with appropriate font, symbols and graphics? • How will information from the group feed back into decisions about service provision? • Will the group be involved in policy and decision-making processes from the outset? How will this happen? • Are group members supported and encouraged to develop roles within the group? How will shift in power relationships be managed?

Communication
<ul style="list-style-type: none"> • Are different communication methods supported and respected within the group? • Are quieter, less confident members given time and encouragement to contribute to group discussions?
Speakers and requests for involvement
<ul style="list-style-type: none"> • Is it appropriate for speakers to visit the group? • Does a speaker wish to discuss issues or to promote their service? • Have speakers been briefed on what is expected of them (such as using accessible language)?
Support workers and personal assistance
<ul style="list-style-type: none"> • Are support workers present during meetings? If so, are they supporting the person to contribute to the meeting? Will the presence of direct care workers inhibit critical feedback on service provision? • Are members' personal assistance requirements understood and addressed?
Service responsibilities
<ul style="list-style-type: none"> • Are the service and parallel group(s) responsible for quality committed to act upon the group's views? • Is the service aware of the time-frames and resources necessary for a group to exist? • Is the group enabled to contribute to service development in a meaningful way?

This summary has been compiled by Melanie Chapman (Research Associate, MLDP) and the members and organisers of *Think Quality*.

For further information about the research project please contact Melanie Chapman.

For further information about *Think Quality* please contact Jackie Kilbane. They are both based at:

Manchester learning Disability Partnership
Oakwood Resource Centre
177 Longley Lane
Northenden
Manchester
M22 4HY

Tel: 0161 998 7424

Email: melc@mldp.freeseve.co.uk

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